

Judith A. Monroe, M.D. State Health Commissioner

Sue Uhl Deputy State Health Commissioner

Office of Minority Health

Epidemiology Resource Center

Robert Teclaw, D.V.M., M.P.H., Ph.D., Director

Surveillance Investigation Unit

Pam Pontones, Director

Author

Antoniette Holt, M.P.H., B.S.P.H.

Contributing Staff

Epidemiology Resource Center Data Analysis Team:
Jon Lewis, Ph.D., Director
Susan Dorrell, B.S.
Matt Kaag, B.S.
Michele Starkey, B.S.
Linda Stemnock, B.S.P.H.

Indiana State Department of Health Minority Health Advisory Committee Edwin C. Marshall, O.D., M.P.H., Chair

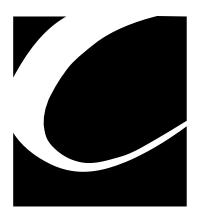
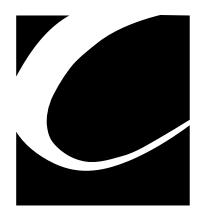


Table of Contents

2004 Indiana Minority Health Report

Preface	
Technical Notes	vi
Introduction	1
Indiana State Department of Health Mission	2
A Review of the 2001 Minority Health Report	2
Eliminating Health Disparities	2
Responsibility of the State	
Goal	
Minority Health in the United States	
Blacks/African Americans	
American Indians/Alaska Natives	
Asian Americans	
Native Hawaiians or Other Pacific Islanders (NHOPI)	
Hispanics or Latinos	
Leading Causes of Death in the United States	9
Indiana's Minority Health Plan	. 11
Heart Disease	. 14
Cancer	. 15
Stroke	. 16
Asthma	. 17
Diabetes	. 18
HIV/AIDS	. 19
Infant Mortality	. 20
Minority Health in Indiana	. 21
Indiana's Counties with the Highest Populations of Racial and Ethnic Minorities, 20	
	22
Leading Causes of Death for Racial/Ethnic Minorities in Selected Counties	
Trends in the Leading Causes of Death for Indiana	
Years of Potential Life Lost	
Health Care Challenges Facing Racial and Ethnic Minorities	
Quality of Care	
Racial Bias in Health Care	. 38
Workforce Diversity	. 40
Language: Where are we going? Importance of Collecting Primary Language Data	. 41
Legal Basis for Collection of Racial, Ethnic Minorities and Primary Language Data	. 42
Published Reports	. 43
Limitations and Suggestions	. 47
Data Limitations	. 48
Suggestions	. 48
Current Data Limitations	. 49
Is Collection of Race and Ethnicity Legal?	. 49
Looking at More than Chronic Disease	
Observational Data Collection	
Summary	. 52
Bibliography, Data Resources, and Helpful Web Sites	

Appendix A – Health Disparities Quick Facts				
African American/Black				
American Indian/Alaska Native	60			
Asian American/Pacific Islander	61			
Hispanic/Latino	62			
Appendix B – Years of Potential Life Lost, Indiana, 2002				



Preface

Welcome to the 2004 Indiana Minority Health Report. This report was commissioned by the Indiana State Department of Health (ISDH) Office of Minority Health and the Indiana Minority Health Advisory Committee to highlight possible trends in certain areas of diseases that most adversely affect racial and ethnic minorities. The 2004 Indiana Minority Health Report is part of the ongoing effort to eliminate health disparities among racial and ethnic minorities.

The 2004 Indiana Minority Health Report provides a snapshot of trends in minority health in Indiana and the United States. The 2004 report updates much of the content in the 2001 Indiana Minority Health Report, which provided the epidemiologic foundation for the Indiana-specific objectives derived in the Healthy Indiana — A Minority Health Plan for the State of Indiana (the Healthy Indiana Minority Health Plan). Developed by the Indiana Minority Health Advisory Committee and released in 2003, the Healthy Indiana Minority Health Plan provides recommended actions, targets for change, and suggested policies to help guide health agencies and other entities in addressing minority health disparities in Indiana.

The 2004 Indiana Minority Health Report continues the series of Indiana reports with a charting of state change since the 2001 report and the release of the Healthy Indiana Minority Health Plan.

"The future health of the nation will be determined to a large extent by how effectively we work with communities to reduce and eliminate health disparities between non-minority and minority populations experiencing disproportionate burdens of disease, disability, and premature death."

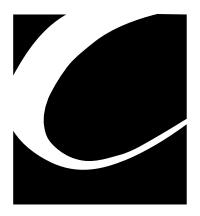
~ Guiding Principle for Improving Minority Health

The 2004 Minority Health Report also provides an overview of some of the health care challenges that face racial and ethnic minorities throughout the country—challenges that must be addressed in Indiana if we are to eliminate racial and ethnic health disparities in the state. The future health of Indiana and the nation as a whole will be influenced considerably by our achievement in improving the health of racial and ethnic minorities.

Primary resources used for this report include: the Indiana Mortality Database, ISDH Epidemiology Resource Center Data Analysis Team; Centers for Disease Control and Prevention, National Center for Health Statistics; Census Bureau; Indiana Department of Education; the National Center for Injury Prevention and Control; and various public health journals.

We would like to thank all those individuals and organizations who have made a commitment to eliminating health disparities. To those who have an interest in furthering this mission and want to know more about minority health, we invite you to become involved with the ISDH Office of Minority Health, the Indiana Minority Health Advisory Committee, and other agencies whose focus is minority health.

The mission of the ISDH Office of Minority Health is to identify and assess the health needs of minorities who experience difficulties accessing preventive and basic health care services.



Technical Notes

Age-Adjusted Death Rate — When comparing rates over time or across different populations, crude rates (the number of deaths per 100,000 persons) can be misleading because differences in the age distribution of the various populations are not considered. Since death is age-dependent, the comparison of crude rates of death can be especially deceptive.

Age adjustment, using the direct method, is the application of age-specific rates in a population of interest to a standardized age distribution in order to eliminate differences in observed rates that result from age differences in population composition. This adjustment is usually done when comparing two or more populations at one point in time or one population at two or more points in time. (National Center for Health Statistics [NCHS])

The direct method of adjustment was used to produce the age-adjusted rates for this report. In this method, the population is first divided into reasonably homogenous age ranges, and the age-specific rate is calculated for each age range. Then, each age-specific rate is weighted by multiplying it by the proportion of the standard population in the respective age group. The age-adjusted rate is the sum of the weighted age-specific rates. Further information regarding the calculation of age-adjusted rates can be found in *The Methods and Materials of Demography*, by Henry S. Shryock, Jacob S. Siegel and Associates, U.S. Department of Commerce.

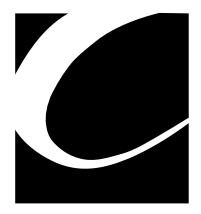
Age adjustment by the direct method requires use of a standard age distribution. The year 2000 population replaces the 1940 U.S. population for age adjusting mortality statistics. The 2000 standard population also replaces the 1970 civilian non-institutionalized population and 1980 U.S. resident population, which previously had been used as standard age distributions for age adjusting estimates from NCHS surveys. The year 2000 standard has implications for race and ethnic differentials in mortality (National Vital Statistics Report, Volume 47, Number 3).

Cause of Death Classification – According to the NCHS, the International Classification of Diseases (ICD) is the classification used to code and classify mortality data from death certificates. NCHS serves as the World Health Organization (WHO) Collaborating Center for the Family of International Classifications for North America and, in this capacity, is responsible for coordination of all official disease classification activities in the U.S. relating to the ICD and its use, interpretation, and periodic revision.

The death statistics presented in this report were compiled in accordance with WHO regulations, which specify that member nations classify cause of death by the current International Classification of Diseases, Injuries and Causes of Death, Ninth Revision (ICD-9) for the years 1995-1998. For the years 1999 and beyond, the cause of death was coded using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10).

Data Limitations – Lack of consensus when defining and measuring race and ethnicity leads to limitations. Particular rates in this report are based on a small population size, a small number of deaths, or both. The rates based on small numbers may be unstable due to random variation and should be used with caution. For rates based on 20 or fewer deaths, the data is considered statistically unstable; thus, valid comparisons are not possible.

Race/Ethnicity – Data presented for the years 1995-2002 was collected using the standards for the classification of federal data on race and ethnicity that were in effect prior to the 2000 Census: White; Black; American Indian, Eskimo, or Aleut (AIEA); Asian/Pacific Islander (API); and Hispanic.



Introduction

Indiana State Department of Health Mission

The Indiana State Department of Health (ISDH) serves to *promote*, *protect*, and *provide* for the public health of people in Indiana. Because of its commitment to enhancing public health in Indiana, the ISDH uses the *Healthy People 2010* goals to improve health within Indiana.

A Review of the 2001 Minority Health Report

The 2001 Indiana Minority Health Report was commissioned by the ISDH Office of Minority Health and the Indiana Minority Health Advisory Committee to compare the leading causes of morbidity and mortality among racial and ethnic groups in Indiana with national data and with benchmarks established in *Healthy People 2010*.

The intent of the 2001 report was to provide information to assess the changing health status of Indiana's racial and ethnic communities and to serve as a guide for developing resources and interventions aimed at eliminating health disparities. The report identified 15 disease areas requiring attention in Indiana, based on the epidemiology of those diseases and, particularly, on their prevalence in and impact on Indiana's racial and ethnic minority populations.

Eliminating Health Disparities

According to the Centers for Disease Control and Prevention (CDC), "The demographic changes that are anticipated over the next decade magnify the importance of addressing disparities in health status. Groups currently experiencing poorer health status are expected to grow as a proportion of the total U.S. population; therefore, the future health of America as a whole will be influenced substantially by our success in improving the health of these groups. A national focus on disparities in health status is particularly important as major changes unfold in the way in which health care is delivered and financed."

Eliminating racial and ethnic disparities in health will require enhanced efforts at preventing disease, promoting health, and delivering appropriate care. This will require improved data collection and the use of standardized data to correctly identify all high-risk populations and monitor the effectiveness of health interventions that target these groups.

Eliminating health disparities will also require new knowledge about the characteristics of disease, underlying causes of health disparities, barriers to improved access to health care services, and collaboration with existing organizations (state and local governments, academia, national and community-based organizations, and local communities) to formulate successful interventions for prevention and treatment.

Responsibility of the State

The Indiana State Department of Health (ISDH) has responsibilities designated by Indiana Code 16-46-11, Chapter 11. Minority Health Initiatives, which states:

The state department of health, in partnership with the Indiana Minority Health Coalition, Inc., shall do the following:

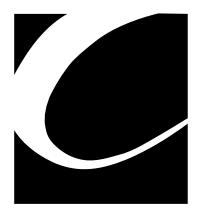
(2) Expand, develop, and implement a community based state structure that is conducive to addressing the health disparities of the minority populations in Indiana.

Examples of the ISDH's implementation of this law include providing assistance to local communities in obtaining funding for the development of a health care delivery system to meet the needs, gaps, and barriers identified in the local plans. The ISDH has also conducted research within minority populations and has worked to develop and implement culturally and linguistically appropriate health promotion and disease prevention programs.

Goal

The ISDH wants every person in Indiana to have equal access to health care and achieve his or her optimal health. Due to the ISDH's dedication to eliminating disparities, this sequel to the 2001 report is designed to demonstrate if the existing health disparities among the different racial/ethnic communities in Indiana found in 1995-2002 have improved.

The 2004 Indiana Minority Health Report compares leading causes of death for each race, years of potential life lost, and areas with limited English proficiency. Recent population data, synopsis of the goals of the 2003 Healthy Indiana Minority Health Plan, and current statistics are also included. The report also examines the limitations that exist in relation to data collection among racial and ethnic minorities.



Minority Health in the United States

The following information on racial and ethnic populations is from the Centers for Disease Control and Prevention, Office of Minority Health, 2004.

Blacks/African Americans

The United States Office of Management and Budget (OMB) has defined Blacks or African Americans as people having origins in any of the black racial groups of Africa. According to the 2000 U.S. Census, those who identify only as African American constitute approximately 12 percent of the American population, or almost 35 million individuals. The Census Bureau projects that, by the year 2035, there will be more than 50 million African Americans in the United States, comprising 14.3 percent of the population. The African-American population is represented throughout the country, with the greatest concentrations in the Southeast and mid-Atlantic regions.

African Americans have a long history in the United States. Some African-American families have been in the United States for many generations; others are recent immigrants from places such as Africa, the Caribbean, or the West Indies. The health disparities between African Americans and other racial groups are striking and are apparent in life expectancy, infant mortality, and other measures of health status. In 1999, the average American could expect to live 76.9 years, whereas the average African American could expect to live only 71.4 years. Factors contributing to poor health outcomes among African Americans include discrimination, cultural barriers, and lack of access to health care.

In addition, nationally, Blacks or African Americans have a disproportionately high prevalence of the following conditions and risk factors:

- Hypertension
- Infant Mortality
- Asthma
- Homicide
- HIV/AIDS
- Diabetes

American Indians/Alaska Natives

American Indians and Alaska Natives (AI/AN) are defined as people having origins in any of the original peoples of North and South America (including Central America) and who maintain tribal affiliation or community attachment. According to the 2000 U.S. Census, those who identify only as AI/AN constitute 0.9 percent of the United States population, or approximately 2.5 million individuals. The Census Bureau projects modest growth by AI/AN communities in the next few decades, topping 5 million individuals by the year 2065 and comprising 1.1 percent of the population. The greatest concentrations of AI/AN populations are in the West, Southwest, and Midwest.

There are 569 federally recognized AI/AN tribes, plus an unknown number of tribes that are not federally recognized. Each tribe has its own culture, beliefs, and practices.

AI/ANs have a unique relationship with the federal government due to historic conflict and subsequent treaties. Tribes exist as sovereign entities, but federally recognized tribes are entitled to health and educational services provided by the federal government. Though the Indian Health Service (IHS) is charged with serving the health needs of these populations, more than half of the AI/AN population do not permanently reside on a reservation and, therefore, have limited or no access to IHS services.

Geographic isolation, economic factors, and suspicion toward traditional spiritual beliefs are some of the reasons why health among AI/ANs is poorer than other groups. Other factors that contribute to poorer health outcomes for AI/ANs include cultural barriers, inadequate sewage disposal, and economic factors.

In addition, nationally, AI/ANs have a disproportionately high prevalence of the following conditions and risk factors:

- Mental Health Issues
- Obesity
- Diabetes
- Substance Abuse
- Sudden Infant Death Syndrome

Asian Americans

Asian Americans are defined as people having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent. According to the 2000 U.S. Census, those who identify only as Asian American comprise 3.6 percent of the American population, or approximately 10 million individuals. The Census Bureau projects that the Asian-American population will grow to 37.6 million individuals by the year 2050, comprising 9.3 percent of the population. Asian-American populations are generally concentrated in the western states, the Northeast, and parts of the South.

Asian Americans represent a wide variety of languages, dialects, and cultures as different from one another as from non-Asian groups. Historically, Asian Americans have been overlooked due to the "myth of the model minority." The erroneous myth is the notion that Asian Americans are passive, compliant, and without problems or needs. The effects of this myth have been the failure to take seriously the very real concerns of this population.

Asian Americans represent both extremes of socioeconomic and health indices. While more than a million Asian Americans live at or below the federal poverty level, Asian-American women have a higher life expectancy than any other group. Factors contributing to poor health outcomes for Asian Americans include language and cultural barriers, stigma associated with certain conditions, and lack of health insurance.

In addition, nationally, Asian Americans have a disproportionately high prevalence of the following conditions and risk factors:

- Chronic Lower Respiratory Disease
- Hepatitis B
- HIV/AIDS
- Tobacco Use
- Tuberculosis

Native Hawaiians or Other Pacific Islanders (NHOPI)

Native Hawaiians or Other Pacific Islanders (NHOPI) are defined as people having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands, even if they do not live in the Pacific Islands. According to the 2000 Census, those who identify only as NHOPI comprise 0.1 percent of the American population, or almost 400.000 individuals.

Until 2000, NHOPIs were grouped with Asian Americans in studies of race and ethnicity. The same was true and continues at the Indiana State Department of Health for data collection purposes. There are no population growth projections for NHOPIs at this time. NHOPIs live throughout the United States, but their populations are most concentrated in the western mainland states and Hawaii.

Though historically grouped with Asian Americans for data collection, NHOPI was assigned as a distinct category for the 2000 Census. NHOPIs generally experience poorer health than the American population as a whole. They are at increased risk for developing and dying from cancer, heart disease, diabetes, and other diseases. Factors contributing to poor health outcomes among NHOPIs include cultural barriers, limited access to health care, and poor nutrition.

In addition, nationally, NHOPIs have a disproportionately high prevalence of the following conditions and risk factors:

- Hepatitis B
- Tuberculosis
- HIV/AIDS

Hispanics or Latinos

Hispanics or Latinos are defined as persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. This is the fastest growing racial and ethnic minority group in Indiana as well as throughout the U.S. The federal government considers race and Hispanic origin to be two separate and distinct concepts; Hispanic or Latino Americans may be any race. According to the 2000 U.S. Census, Hispanics or Latinos of all races represent 12.5 percent of the U.S. population, or about 35 million individuals. The Census Bureau projects that, by the year 2035, there will be 75 million Hispanic or Latino individuals, comprising 20 percent of

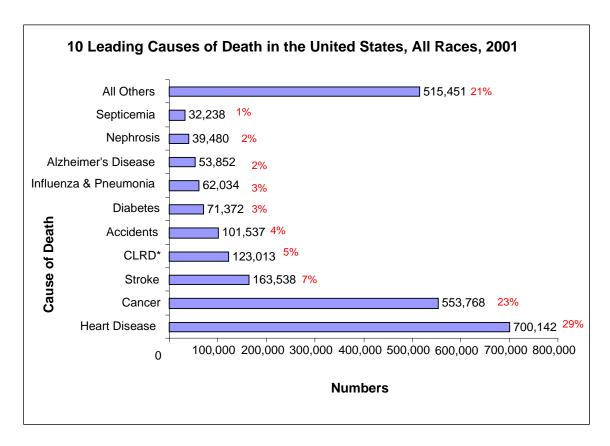
the population. Though Hispanic or Latino communities can be found throughout Florida, the Northeast, and other parts of the country, the greatest concentrations of Hispanics or Latinos are in the southwestern states.

Though they share many aspects of a common heritage such as language and emphasis on extended family, Hispanic or Latino cultures vary significantly by country of origin. Hispanics/Latinos tend to be younger than the white non-Hispanic population (except for Cubans, who have a higher proportion of elderly than other Hispanic groups). Their health profiles are also unique: Puerto Ricans suffer disproportionately from asthma, HIV/AIDS, and infant mortality, while Mexican Americans suffer disproportionately from diabetes. Factors that contribute to poor health outcomes among Hispanics/Latinos include language and cultural barriers, lack of access to preventive care, and lack of health insurance.

In addition, nationally, Hispanics or Latinos have a disproportionately high prevalence of the following conditions and risk factors:

- Chronic Obstructive Pulmonary Disease
- Asthma
- Accidents
- Suicide
- Obesity
- Teenage Pregnancy
- HIV/AIDS

Leading Causes of Death in the United States



^{*}Chronic Lower Respiratory Disease

Source: National Center for Health Statistics (NCHS), National Vital Statistics System, 2001

Leading Causes of Death for Each Race and Ethnicity in U.S., 2001



American Indian/Alaska Native

- 1. Heart Disease
- 2. Cancer
- 3. Accidents
- 4. Diabetes
- 5. Stroke
- 6. Liver Disease
- 7. CLRD
- 8. Suicide
- 9. Influenza and Pneumonia
- 10. Kidney Disease

Black/African American

- 1. Heart Disease
- 2. Cancer
- 3. Stroke
- 4. Accidents
- 5. Diabetes
- 6. Homicide
- 7. HIV/AIDS
- 8. CLRD
- 9. Kidney Disease
- 10. Septicemia

Asian/Pacific Islander

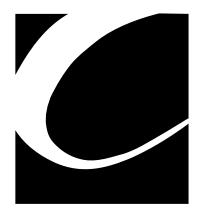
- 1. Cancer
- 2. Heart Disease
- 3. Stroke
- 4. Accidents
- 5. Diabetes
- 6. CLRD
- 7. Influenza and Pneumonia
- 8. Suicide
- 9. Kidney Disease
- 10. Homicide

Hispanic/Latino

- 1. Heart Disease
- 2. Cancer
- 3. Accidents
- 4. Stroke
- 5. Diabetes
- 6. Homicide
- 7. Liver Disease
- 8. CLRD
- 9. Influenza and Pneumonia
- 10. Conditions During Perinatal Period



^{*}Source: National Center for Health Statistics (NCHS), National Vital Statistics System, 2001



Indiana's Minority Health Plan

The Indiana Minority Health Advisory Committee (InMHAC) was created in 2000 by the Indiana State Department of Health (ISDH) to provide the agency with advice and guidance in addressing minority health disparities. Subsequently, the committee was charged with the task of proposing a plan for eliminating racial and ethnic health disparities in Indiana. In preparation for its task, the committee adopted the mission statement of "Hoosiers working together to *HEAL the GAP* in racial and ethnic health disparities for all people in Indiana." Its vision is to propose a plan in which Hoosiers work together to eliminate racial and ethnic health disparities for all people in Indiana through the process of **HEAL:**

- Health (promoting a state of complete physical, mental, social, and spiritual wellbeing),
- Equality (ensuring culturally sensitive quality health care and outcomes),
- Access (removing all barriers to increase the quality and years of healthy life),
- Leadership (actualizing goals through collaborative partnerships, innovative relationships, and community involvement).

The State of Indiana, through the Indiana State Department of Health and the Minority Health Advisory Committee, proposed a plan of collaboration with public and private partners to address the goal of eliminating racial and ethnic health disparities in Indiana. *Healthy Indiana – A Minority Health Plan for the State of Indiana* (the Healthy Indiana Minority Health Plan) was founded on four overarching strategic goals:

- 1. Prepare evidence-based documentation of racial and ethnic health disparities in Indiana.
- 2. Develop interventions to eliminate racial and ethnic health disparities in Indiana.
- 3. Identify and solidify effective public/private, community-based partnerships to help develop, implement, evaluate, and assess outcomes of the proposed interventions.
- 4. Eliminate disparities in health, based on race or ethnicity among Indiana residents, such that the gap for any disease is less than 5 percent.

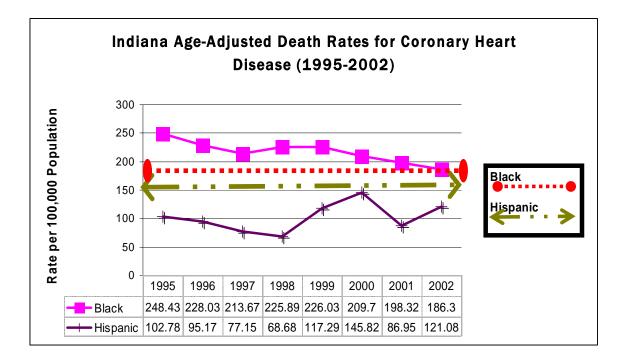
The Healthy Indiana Minority Health Plan flows directly from the 2001 Indiana Minority Health Report and Healthy People 2010. The plan uses the 2001 Indiana Minority Health Report in a data-driven, evidence-based, community-centered, multidisciplinary approach to assess documented gaps in health status and identify critical areas of intervention for Indiana's racial and ethnic minority populations (using the standards for classification prior to the 2000 Census: American Indian/Eskimo/Aleut [AIEA], Asian/Pacific Islander [API], Black, Hispanic).

Due to some racial and ethnic populations being lower in number than others (AIEA and API), which resulted in not having enough data for numbers to be statistically sound, the plan focused primarily on the Black and Hispanic populations. Also, there are some diseases where Hispanic numbers were below or exactly average; therefore, no goal was set for Hispanics in these scenarios.

The Healthy Indiana Minority Health Plan focused on seven diseases: heart disease, cancer, diabetes, stroke, infant mortality, asthma, and HIV/AIDS. The following graphs benchmark Indiana's 1995-2002 disease trends against the Healthy Indiana Minority Health Plan's 2010 goals for Indiana. The dotted red line represents the goal for Blacks, and the dashed green line represents the goal for Hispanics.

HEART DISEASE

- 1. *Goal:* Reduce coronary heart disease death rate among Indiana's Black or African-American population to 170.3 deaths per 100,000 Black or African-American persons (CVD-1/HP2010 Ref: 12-1; Healthy Indiana Minority Health Plan).
- 2. *Goal:* Reduce coronary heart disease death rate among Indiana's Hispanic or Latino population to 161.1 deaths per 100,000 Hispanic or Latino persons (CVD-2/HP2010 Ref: 12-1; Healthy Indiana Minority Health Plan).

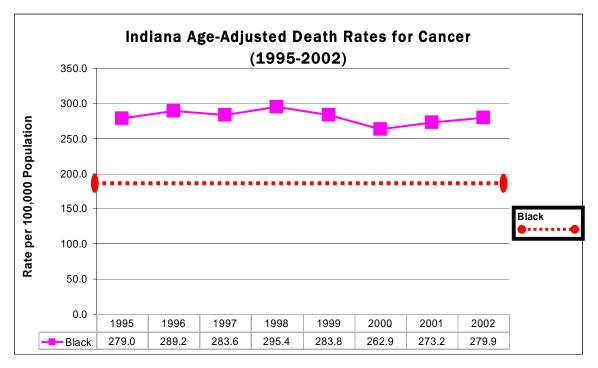


Rates are per 100,000 population.

Hispanic is an ethnicity and includes all races.

CANCER

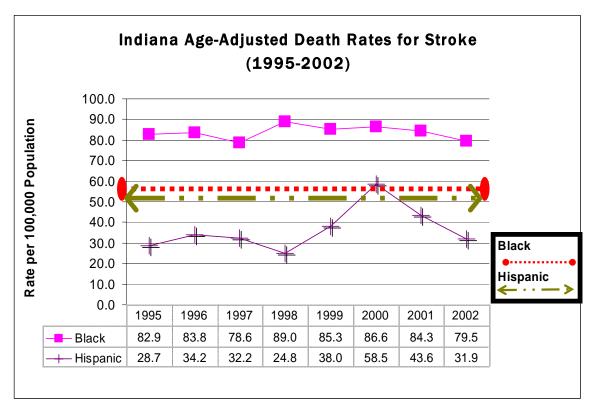
1. *Goal:* Reduce the overall cancer death rate among Indiana's Black or African-American population to 192.4 deaths per 100,000 Black or African-American persons (CAN-1/HP2010 Ref: 3-1; Healthy Indiana Minority Health Plan).



Rates are per 100,000 population.

STROKE

- 1. *Goal:* Reduce the stroke death rate among Indiana's Black or African-American population to 55.4 deaths per 100,000 Black or African-American persons (STR-1/HP2010 Ref: 12-7; Healthy Indiana Minority Health Plan).
- 2. *Goal:* Reduce the stroke death rate among Indiana's Hispanic or Latino population to 53.1 deaths per 100,000 Hispanic or Latino persons (STR-2/HP2010 Ref: 12-7; Healthy Indiana Minority Health Plan).

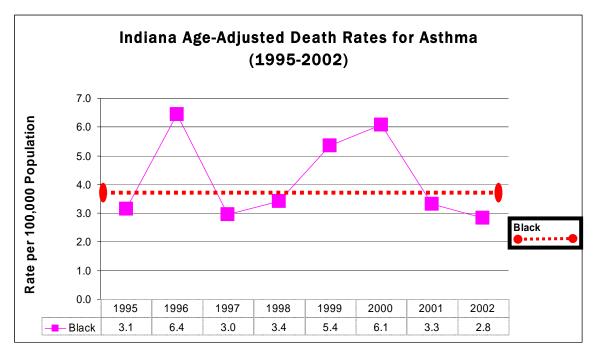


Rates are per 100,000 population.

Hispanic is an ethnicity and it includes all races.

ASTHMA

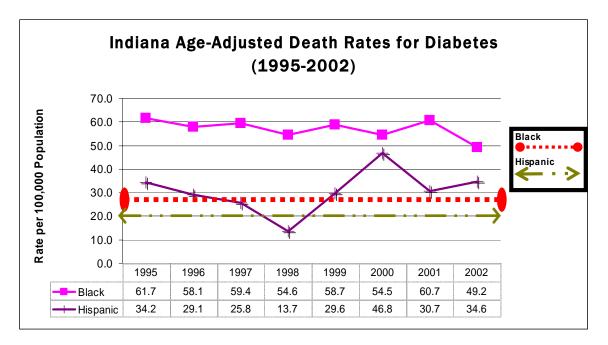
1. *Goal*: Reduce the asthma death rate among Indiana's Black or African-American population to 3.8 deaths per 100,000 Black or African-American persons (AST-1/HP2010 Ref: 24-1; Healthy Indiana Minority Health Plan).



Rates are per 100,000 population.

DIABETES

- 1. *Goal:* Reduce the diabetes death rate among Indiana's Black or African-American population to 28.7 deaths per 100,000 Black or African-American persons (DIA-2/HP2010 Ref: 5-5; Healthy Indiana Minority Health Plan).
- 2. *Goal:* Reduce the diabetes death rate among Indiana's Hispanic or Latino population to 25.9 deaths per 100,000 Hispanic or Latino persons (DIA-3/HP2010 Ref: 5-5; Healthy Indiana Minority Health Plan).



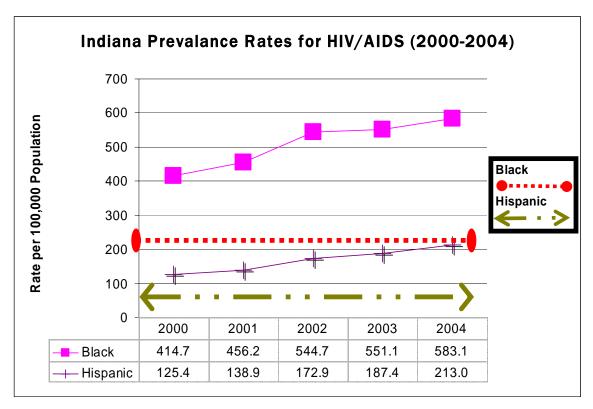
Rates are per 100,000 population.

Hispanic is an ethnicity and it includes all races.

HIV/AIDS

The Healthy Indiana Minority Health Plan has a goal for HIV/AIDS prevalence, not for deaths. Therefore, it cannot be compared with death data.

- 1. *Goal:* Reduce the prevalence of HIV/AIDS among Indiana's Black or African-American population to 250.0 cases of HIV/AIDS per 100,000 Black or African-American persons (HIV-1, HP2010 Ref: 13-1; Healthy Indiana Minority Health Plan).
- 2. *Goal:* Reduce the prevalence of HIV/AIDS among Indiana's Hispanic or Latino population to 79.1 cases of HIV/AIDS per 100,000 Hispanic or Latino persons (HIV-2, HP2010 Ref: 13-1; Healthy Indiana Minority Health Plan).

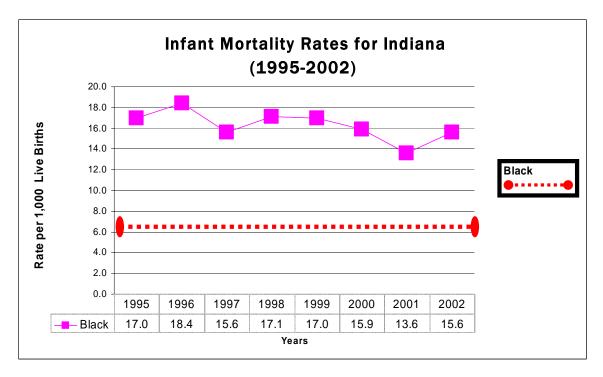


Rates are per 100,000 population. Hispanic is an ethnicity and it includes all races.

INFANT MORTALITY

Infant mortality is a crucial gauge of the health and welfare of any population. The infant mortality rate in the U.S. has dropped steadily since 1950, reaching 7.0 deaths per 1,000 live births in 2001. The U.S. continues to have a higher infant mortality rate than other developed countries. One reason is the higher infant death rates among minority groups, particularly Blacks or African Americans, for whom infant mortality remains a serious public health problem. In Indiana, the infant mortality rate is higher for Blacks or African Americans than for any other race or ethnicity.

1. *Goal:* Reduce the infant mortality rate among Indiana's Black or African-American population to 6.7 per 1,000 live births (reduce to the rate for Indiana's white population) (IMR-1, HP2010 Ref: 16-1c; Healthy Indiana Minority Health Plan).



Rates are per 1,000 live births.



Minority Health in Indiana

Indiana's Counties with the Highest Populations of Racial and Ethnic Minorities, 2002

	African American/		Asian/		American Indian/		Hispanic/	
	Black		Pacific Islander		Alaska Native		Latino	
County Name	Number	Percent within State Population	Number	Percent within State Population	Number	Percent within State Population	Number	Percent within State Population
Total								
Population	525,151	100%	72,523	100%	17,249	100%	236,367	100%
Allen	38,653	7%	5,704	8%	1,289	7%	15,654	7%
Delaware	7,960	2%	954	1%	279	2%	1,362	1%
Elkhart	9,531	2%	2,205	3%	576	3%	18,990	8%
Hamilton	4,420	1%	6,879	9%	346	2%	3,875	2%
Kosciusko	496	0%	461	1%	209	1%	3,993	2%
Lake	124,178	24%	4,806	7%	1,656	10%	61,580	26%
LaPorte	11,055	2%	577	1%	363	2%	3,778	2%
Madison	10,463	2%	527	1%	331	2%	2,135	1%
Marion	215,944	41%	14,643	20%	2,450	14%	38,922	16%
Miami	1,009	0%	139	0%	402	2%	455	0%
Monroe	3,466	1%	4,639	6%	330	2%	2,403	1%
Noble	234	0%	200	0%	135	1%	3,871	2%
Porter	1,847	0%	1,624	2%	377	2%	7,690	3%
St. Joseph	30,706	6%	4,381	6%	1,018	6%	13,558	6%
Tippecanoe	3,777	1%	7,397	10%	460	3%	8,660	4%
Vanderburgh	13,931	3%	1,636	2%	304	2%	1,757	1%
Total	477,670	91%	56,772	78%	10,525	61%	188,683	80%

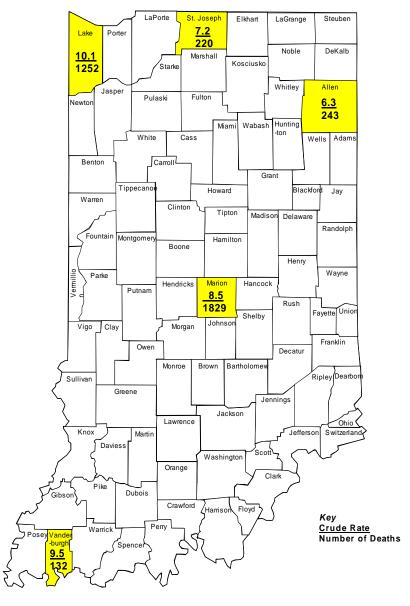
Source: U.S. Census Bureau, Census 2002 Estimation Data/Redistricting Data (Public Law 94-171) Summary File, Matrices PL1 and PL2.

Hispanic includes all races.

Leading Causes of Death for Racial/Ethnic Minorities in Selected Counties

In this section, maps are provided for each racial and ethnic group to show crude (death) rates in those counties with the highest number of deaths for racial and ethnic minorities in 2002. This section shows a comparison of deaths and death rates. It is important to note that the rate based on numbers lower than 20 deaths are statistically unstable, and extreme caution must be used when interpreting data.

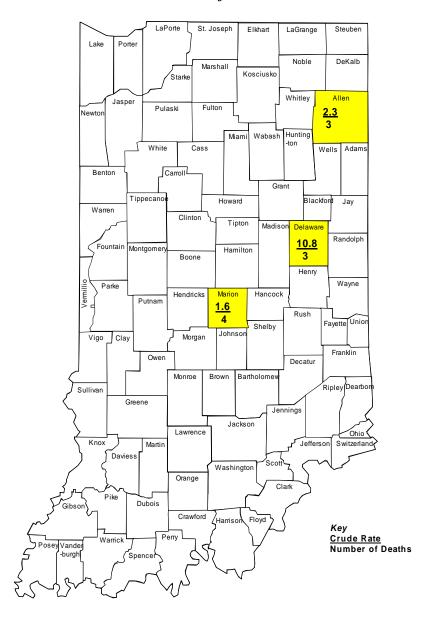
Crude Rates and Death Numbers for African Americans/Blacks



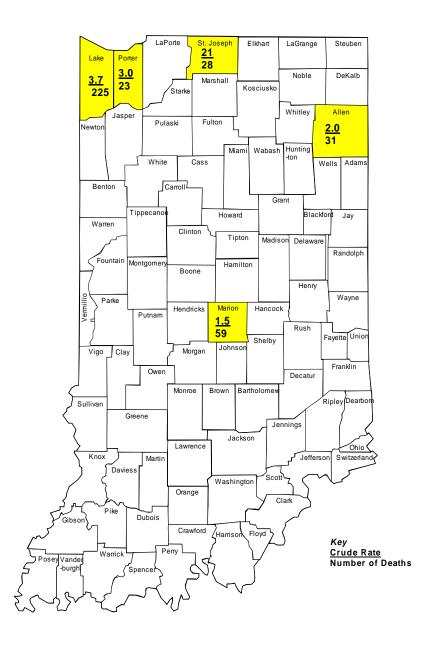
Crude Rates and Death Numbers for Asians/Pacific Islanders



Crude Rates and Death Numbers for American Indians/Alaska Natives



Crude Rates and Death Numbers for Hispanics/Latinos

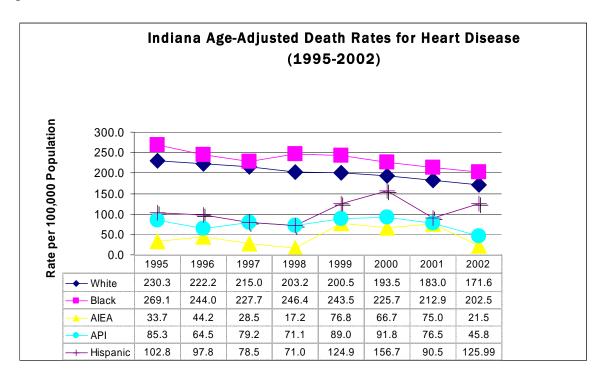


Trends in the Leading Causes of Death for Indiana

The 2001 Minority Health Report focused on the leading causes of death for each racial and ethnic minority group and the disparity gaps among each group. The goal was to inform health professionals and the general public about the identified health gaps and to determine Indiana's success in reducing them. The following tables reveal what progress, if any, has been made in decreasing racial and ethnic disparities in age-adjusted death rates from 1995 to 2002.

The data presented was collected using the standards for the classification of federal data on race and ethnicity that were in effect prior to the 2000 Census: White; Black; American Indian, Eskimo, Aleut (AIEA); Asian, Pacific Islander (API); and Hispanic.

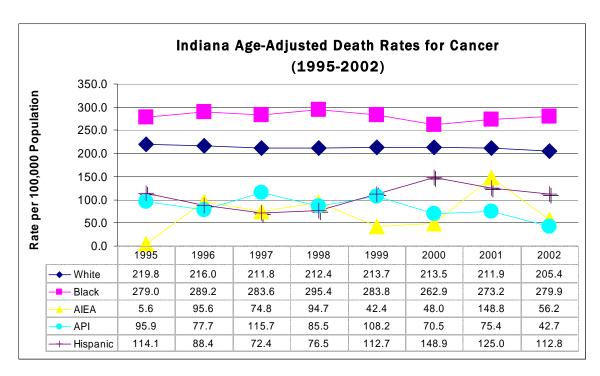
When the number of deaths used to compute the death rates is small, the death rates may become statistically unstable. This is true for certain populations in Indiana, e.g., AIEA, API, and Hispanic. Therefore, to discourage misinterpretation and misuse of the data presented, the statistics should be used with extreme caution.

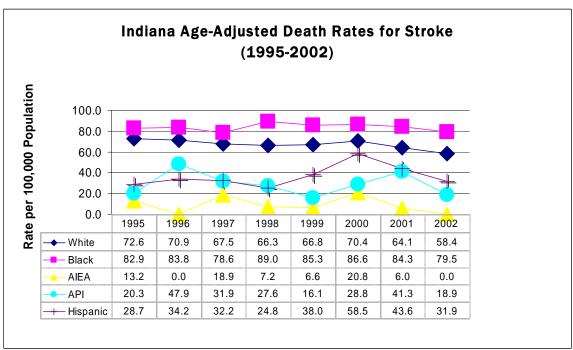


Numbers vary due to population of race or ethnic group being compared. Rates are per 100,000 population.

Hispanic is an ethnicity and it includes all races.

If there are fewer than 20 deaths, the data are considered **statistically unstable**. Populations most affected are the AIEA, API, and Hispanic. **Extreme caution** should be used in interpretation.



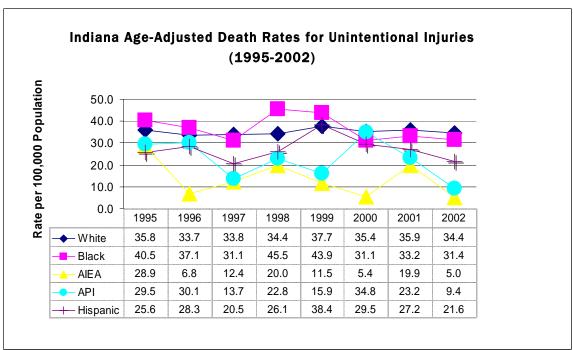


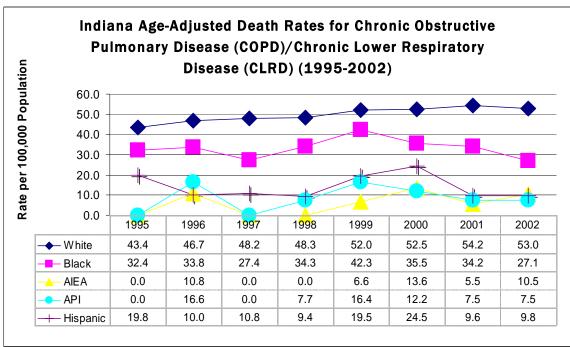
Numbers vary due to population of race or ethnic group being compared.

Rates are per 100,000 population.

Hispanic is an ethnicity and it includes all races.

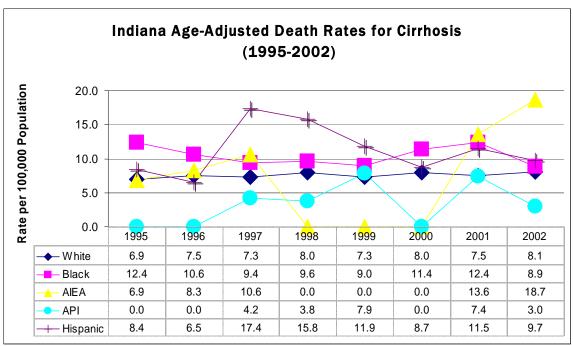
If there are fewer than 20 deaths, the data are considered **statistically unstable**. Populations most affected are the AIEA, API, and Hispanic. **Extreme caution** should be used in interpretation.

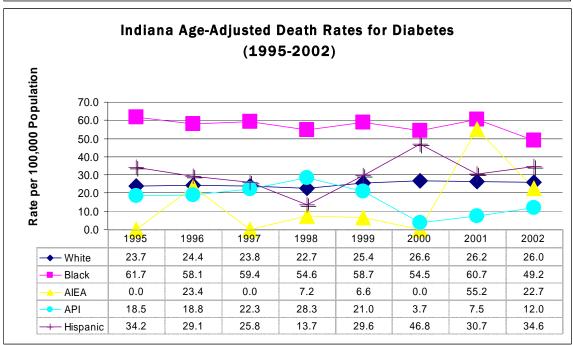




Rates are per 100,000 population.

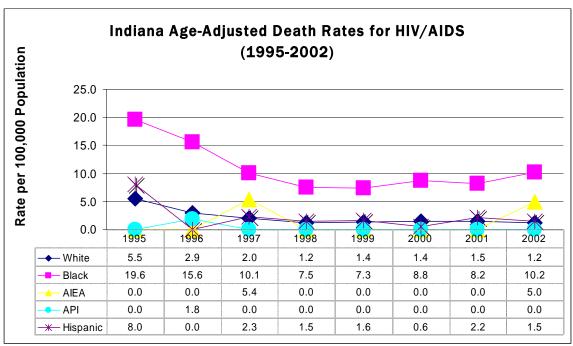
Hispanic is an ethnicity and it includes all races.

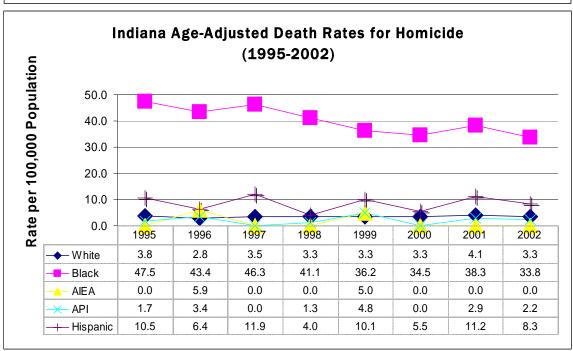




Rates are per 100,000 population.

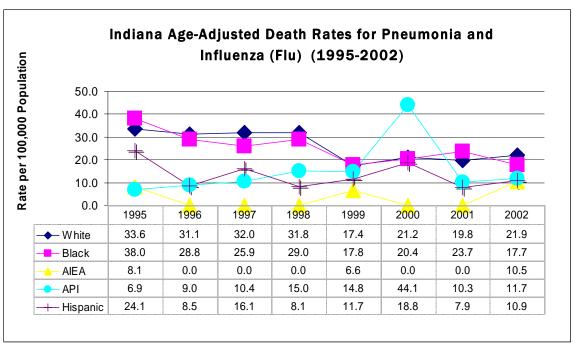
Hispanic is an ethnicity and it includes all races.

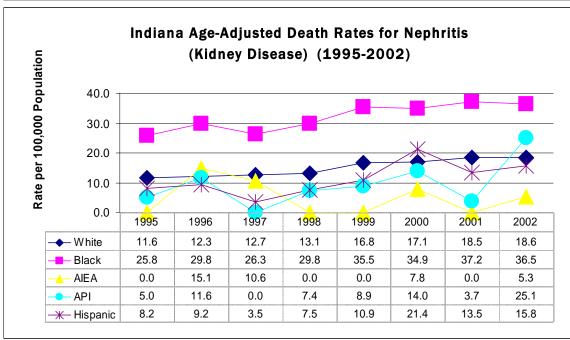




Rates are per 100,000 population.

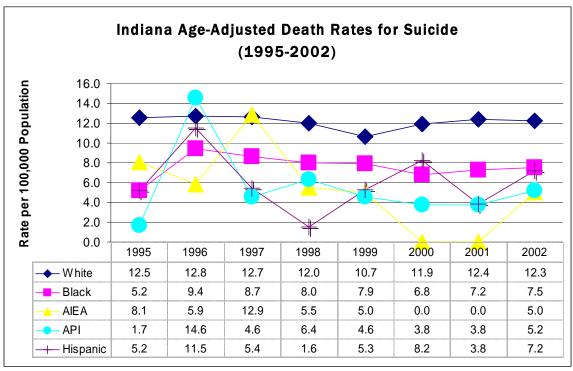
Hispanic is an ethnicity and it includes all races.

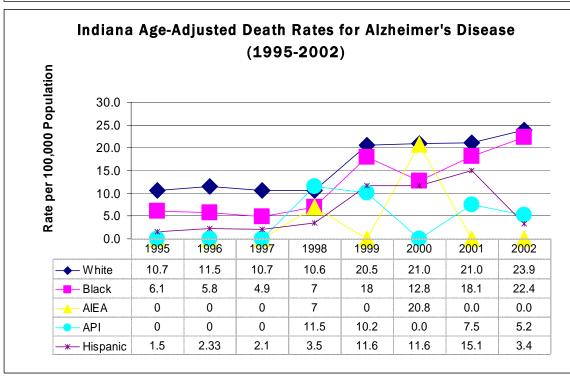




Rates are per 100,000 population.

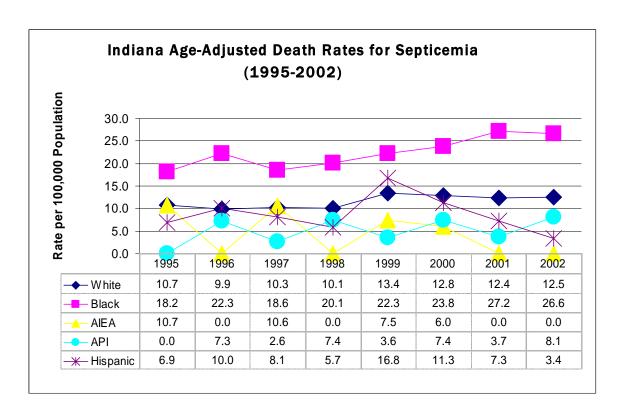
Hispanic is an ethnicity and it includes all races.

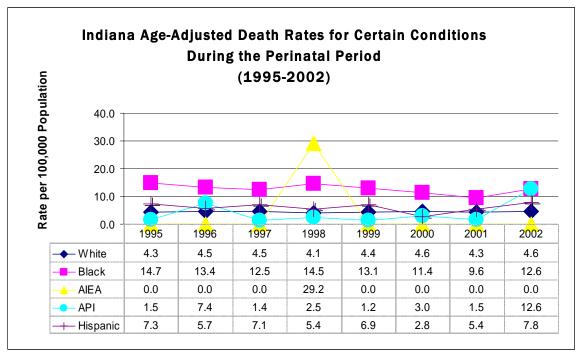




Rates are per 100,000 population.

Hispanic is an ethnicity and it includes all races.





Rates are per 100,000 population.

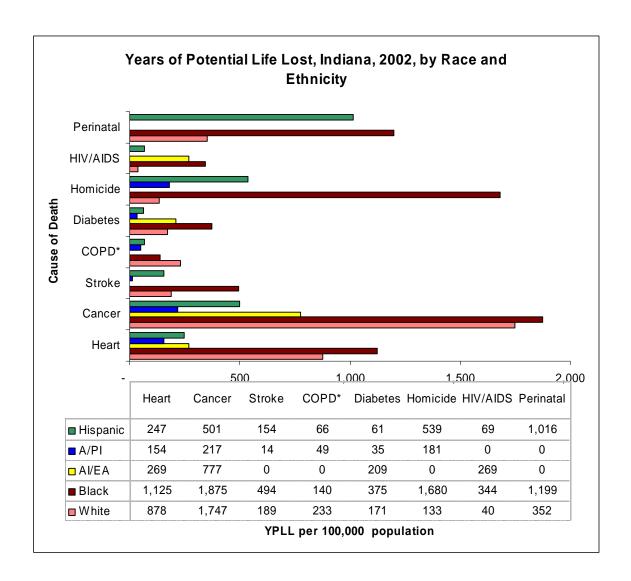
Hispanic is an ethnicity and it includes all races.

Years of Potential Life Lost

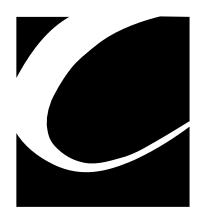
Years of Potential Life Lost (YPLL) is a measurement of premature mortality. When looking at specific state mortality rates, YPLL can be most helpful for planning and evaluating local public health interventions. Examining race-specific YPLL rates can be used to target and monitor those populations at highest risk.

The determination of YPLL life expectancy takes into account race, sex, or other characteristics using age-specific death rates for the population with that characteristic. The National Center for Health Statistics (NCHS) definition of YPLL is presented for persons less than 75 years of age, because the average life expectancy in the United States is just over 75 years (mean 76.7). YPLL for persons under 75 is calculated using the following eight age groups: less than 1 year, 1-14 years, 15-24 years, 25-34 years, 35-44 years, 45-54 years, 55-64 years, and 65-74 years. The number of deaths for each age group is multiplied by the years of life lost, calculated as the difference between age 75 years and the midpoint of the age group. Summing years of life lost over all age groups derives YPLL (YPLL data provided by the National Vital Statistics System and the *Health, United States*, 2001 CDC publication).

The following chart shows the age-adjusted YPLL for specific diseases and by race and ethnicity to reflect a more accurate comparison of differences between each race and ethnicity.



^{*}Chronic Obstructive Pulmonary Disease



Health Care Challenges Facing Racial and Ethnic Minorities

Quality of Care

In spite of continuing improvements in health in the United States, racial and ethnic minorities experience greater rates of morbidity and mortality than non-minorities. Disparities in health care exist even when controlling for gender, condition, age, and socioeconomic status.

When examining access to care, racial and ethnic minorities experience a lower quality of health services and are less likely to receive routine medical procedures than non-minorities. Factors that affect quality of health care include:

- Present operations of health care and delivery systems
- Discrimination at the individual patient-provider level
- Lack of cultural competence in regards to overall health

A 2000-2001 study published in the *New England Journal of Medicine* used the Community Tracking Study Physician Survey to perform a cross-sectional analysis of doctor visits by Black Medicare beneficiaries and white Medicare beneficiaries ages 65 years or older. The authors concluded that Black patients and white patients are treated by different physicians. The physicians treating Black patients may be less well trained clinically and may have less access to important clinical resources than physicians treating white patients. (Bach, *NEJM*, August 5, 2004)

Such disparities in health care lead to disparities in health outcomes for racial and ethnic minorities such as:

- Higher rates of illness and mortality
- Disability from unmet health needs
- Higher rates of infection and lower survival rates

Another study published in the *New England Journal of Medicine* found that race and gender influenced the quality of treatment given to patients with cardiovascular disease. (Schulman, *NEJM*, February 25, 1999)

Racial Bias in Health Care

The life expectancy of minority groups in the U.S. continues to be drastically shorter than that of white Americans. Although significant gains have been made in recent years to enhance endurance and reduce the impact of chronic diseases, minority populations have benefited much less than the white population. These disparities in health exist for many reasons, however racial bias appears to contribute significantly to differences in health care.

Several studies have reported that Black patients are less likely than white patients to undergo certain life-saving procedures. Data from the Cooperative Cardiovascular Project, a study of Medicare beneficiaries hospitalized for acute myocardial infarction in

1994 and 1995, evaluated whether differences between Black patients and white patients in the use of cardiac catheterization within 60 days after acute myocardial infarction varied according to the race of the attending physician. Black patients had lower rates of cardiac catheterization than white patients. Another recent study of racial factors that contribute to differentials in diagnosis and treatment demonstrated that racial bias is a significant influence on the likelihood that cardiac catheterization will be recommended for patients with chest pain.

The influence of racial bias is not limited to access to health care. Prejudice and discrimination can be sources of acute and chronic stress, which has been linked to conditions such as cardiovascular disease and alcohol abuse. Discrimination can restrict the educational, employment, economic, residential, and partner choices of individuals, affecting health through pathways linked with what psychosocial scientists refer to as human capital. Environmental influences from industry, toxic waste disposal sites, and other geographic aspects linked with poverty and minority status can result in serious disadvantages to the health of minority groups.

Evidence is insufficient to evaluate the magnitude of the relationship between racial biases and health. In addition, much of the empirical work investigating the effects of prejudice and discrimination and health has focused on African Americans. Few studies have addressed systematically how prejudice and discrimination affect other racial/ethnic minority groups such as American Indians/Alaska Natives, Asian Americans, and Hispanics/Latinos. Prejudice and discrimination have helped shape the social position of each racial and ethnic group in the U.S. and, consequently, they may have unique associations with the health of each group.

These examples emphasize that the persistent effect of discrimination on health might be meditated significantly through its effect on worsening disease status, access to health care, and access to sufficient resources for providers dedicated to taking care of people in communities with fewer resources. In other words, what is the impact of the possibility of individual non-minority physicians making racially biased decisions compared to the impact of evasive discrimination in society contributing to significant gaps in socioeconomic status, poorer health, and accessible resources?

Finally, an insufficient focus on the impact of societal forces has hindered our ability to understand and effectively address the influence of racial biases on health disparities. The growing evidence that health, socioeconomic status, and macro-economics are inextricably linked emphasizes the importance of undertaking a program of research to examine the relative magnitude of the influence of racial bias in the context of the other factors thought to affect minority health.

Workforce Diversity

There is an overwhelming need to increase the number of physicians, particularly physicians of color, who can be invaluable keys to eliminating health disparities. In 2002, the American Medical Student Association (AMSA) stated that racial and ethnic minority doctors will be more likely to:

- Care for the underinsured
- Work in underserved areas
- Treat Medicaid patients

In 2001, only 3.7 percent of active physicians in Indiana were Black or African American, and only 2.5 percent were Hispanic or Latino. (*Indiana Physician Survey, 2001, Databook,* Indiana Health Care Professional Development Commission) What are the reasons for such underrepresentation of racial and ethnic minorities in medicine? Many experts believe that the key to expanding the number of minority health care professionals is through the improvement of the education system.

The AMSA survey conducted in 2002 discovered barriers that racial and ethnic minority students face in the recruitment and admission process of medical school:

- No or underrepresented minority faculty
- No role models
- Low GPA
- Poor science preparation
- Court decisions (Affirmative Action rulings)
- State is not diverse
- Lack of financial aid
- No community support
- Low achievement of parents
- Low MCAT (bias standardized testing)

Daniel J. Delaney, Director of Minority Health Policy for the Massachusetts Health Care For All, stated "Physician diversity is not just important for Blacks, Latinos and other underrepresented minorities in medicine. It has important public health implications for the Commonwealth as a whole. When minorities don't get quality, timely, and culturally appropriate care it reduces their quality of life and further burdens an already strained health care system".

Who Is Affected

In order to improve quality of care, it is necessary to examine not only who is providing the service, but the quality of the patient-provider relationship. Patients with and without health coverage state that their health care providers fail to provide complete information, hurry their prognosis, doctors don't listen to their concerns, show bias, and lack the time needed to provide high quality care.

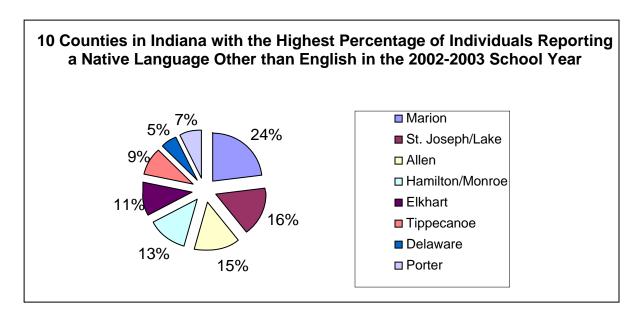
Many physicians believe that they make the best decisions they can under present time constraints and with limited information from the patient. To strengthen doctor-provider relationships with racial and ethnic minorities, research is needed on the quality of the interaction and the provider's awareness of disparities and cultural competence.

Language: Where are we going? Importance of Collecting Primary Language Data

Due to the growing immigrant population of Indiana, more and more cultural beliefs and languages are being integrated. Limited English proficiency has become an issue right here in Indiana. Indiana is becoming more diverse and must raise the standard in providing culturally competent prevention, care, and treatment. According to the Indiana State Department of Education, the following languages were spoken statewide in the 2002-2003 school year:

- Arabic
- German
- Japanese
- Korean
- Mandarin
- Russian
- Spanish
- Urdu
- Vietnamese

The following chart shows the 10 Indiana counties with the highest percentage of individuals reporting a native language other than English in the 2002-2003 school year:

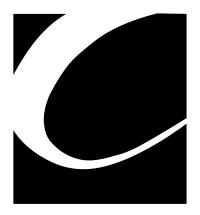


Language data will be crucial to providing services to those who speak English as a second language. Communication cannot occur without the necessary people, skills, tools, or resources.

Legal Basis for Collection of Racial, Ethnic Minorities and Primary Language Data

Title VI of the Civil Rights Act of 1964 "prohibits intentional discrimination on the basis of race or national origin in the provision of any services that are at all supported with federal funds." (Perot, Youdelman, 2001) Title VI covers all programs or any activities of an entity receiving federal financial assistance. Thus, it is illegal to fail to provide necessary health care services or language translation and or interpretive services, but there are no statutes requiring data collection and reporting of primary language data.

The lack of enforcement for data collection of health care service agencies continues to broaden the gap for health disparities. Unless individuals are insured through Medicaid or Medicare, race and ethnicity or primary language is not commonly recorded. It is seen as a hassle rather than a necessity.



Published Reports

1) National Healthcare Disparities Report: Summary. February 2004. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/qual/nhdr03/nhdrsum03.htm

The National Healthcare Disparities Report, developed by the Agency for Healthcare Research and Quality (AHRQ), is the first national comprehensive effort to measure differences in access and use of health care services by various populations. The report includes a broad set of performance measures that can serve as a baseline for demonstrating differences in the use of services. The report presents data on differences in the use of services, access to health care, and impressions of quality for seven clinical conditions, including cancer, diabetes, end-stage renal disease, heart disease, HIV and AIDS, mental health, and respiratory disease as well as data on maternal and child health, nursing home and home health care, and patient safety. It also examines differences in use of services by priority populations.

2) Institute of Medicine (IOM). Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare. (2003) National Academies Press. http://www.iom.edu/

In 1999, the United States Congress requested an IOM study to assess the extent of disparities in the types and quality of health services received by U.S. racial and ethnic minorities and non-minorities, explore factors that may contribute to inequities in care, and recommend policies and practices to eliminate those inequities.

The report from that study, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, found that a consistent body of research demonstrates significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable. This research indicates that U.S. racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services.

The report says a large body of research underscores the existence of disparities. For example, minorities are less likely to be given appropriate cardiac medications or to undergo bypass surgery and are less likely to receive kidney dialysis or transplants. By contrast, they are more likely to receive certain less desirable procedures, such as lower limb amputations for diabetes and other conditions.

The committee's recommendations for reducing racial and ethnic disparities in health care include increasing awareness about disparities among the general public, health care providers, insurance companies, and policymakers.

Further, the report says that consistency and equity of care should be promoted through the use of "evidence-based" guidelines to help providers and health plans make decisions about which procedures to order or pay for based on the best available science. More minority health care providers are needed, especially since they are more likely to serve in minority and medically underserved communities, and more interpreters should be

available in clinics and hospitals to overcome language barriers that may affect the quality of care.

3) Racial and Ethnic Approaches to Community Health (REACH) 2010, Risk Factor Survey Participating Communities and Organizations – United States, 2001-2002 http://www.cdc.gov/reach2010.

Racial and Ethnic Approaches to Community Health (REACH) 2010 is the cornerstone of the CDC's efforts to eliminate racial and ethnic disparities in health. Launched in 1999, REACH 2010 is designed to eliminate disparities in the following six priority areas: cardiovascular disease, immunizations, breast and cervical cancer screening and management, diabetes, HIV/AIDS, and infant mortality. The racial and ethnic groups targeted by REACH 2010 are African Americans, American Indians, Alaska Natives, Asian Americans, Hispanic Americans, and Pacific Islanders.

REACH 2010 supports community coalitions in designing, implementing, and evaluating community-driven strategies to eliminate health disparities. Each coalition comprises a community-based organization and three other organizations, of which at least one is either a local or state health department or a university or research organization.

REACH 2010 grantees are using local data to implement interventions that address one or more of the six priority areas and target one or more racial and ethnic groups. The activities of these community coalitions include continuing education on disease prevention for health care providers, health education and health promotion programs that use lay health workers to reach community members, and health communications campaigns.

4) Sullivan Commission on Diversity in the Healthcare Workforce's report, *Missing Persons: Minorities in the Health Professions* http://www.sullivancommission.org/

Missing Persons: Minorities in the Health Professions emphasizes the need for leadership, commitment, and accountability at the highest levels in institutions of learning and professional organizations, and at the national level in the form of legislation. The report calls for a Presidential task force to give urgency and focus to the problem. Strategies are identified to make education and training in the health professions more attainable and affordable for minority students, including shifting from student loans to scholarships; reducing dependency on standardized tests for admission to schools of medicine, nursing, and dentistry; and enhancing the role of two-year colleges.

In all, 37 separate recommendations are put forward to remedy the lack of diversity among health professionals, warning that failure to act quickly will only exacerbate the current disconnect between health care providers and the populations they serve.

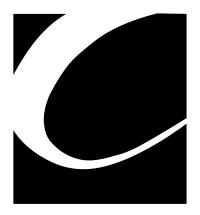
The Sullivan Commission's recommendations were developed to attract broad public support and to encourage academic and professional leadership to share the commission's

vision for a health system modeled on excellence, access, and quality for all people. Three overlying principles are essential to fulfilling that vision:

- 1) To increase diversity in the health professions, the culture of health professions schools must change. Our society is experiencing a significant and rapid demographic shift. The culture of our nation is changing. So, too, must the culture of our health institutions. As colleges, universities, health systems, and others examine these recommendations, they must also examine the practices of their own institutions.
- 2) New and nontraditional paths to the health professions should be explored. In some health professions, it takes between 10 and 12 years to fully educate and train the provider. This commission calls for major improvements in the K-12 educational system, with the realization that the degree of diversity in health professions schools cannot remain stagnant while these improvements take shape.
- 3) Commitments must be at the highest levels. Change can happen when institutional leaders support the change. In 1966, Duke University School of Medicine was one of the last two medical schools in the South to admit a Black student. Today, Duke University School of Medicine has become a model of diversity and has used its leadership to bring other institutions along a new and inclusive path toward excellence.

Racial and ethnic minorities are conspicuously missing from our nation's health professions workforce. In the future, if current trends continue, this workforce will have even less resemblance to the nation's dynamically changing demographic composition. There is a direct link between poorer health outcomes for minorities and the shortage of minority health care providers. The evidence that the Commission reviewed and the testimony it heard led its members to conclude that the condition of the health care workforce is "critical" and demands swift, large-scale change. To increase diversity, the culture of health professions must change; new and traditional paths to the health professions must be explored, and commitments must be at the highest levels from our government and private sectors.

The Sullivan Commission calls upon the leaders in the public and private sectors to act on the report's recommendations.



Limitations and Suggestions

Data Limitations

Assessment of health disparities has been hindered by data collection processes that are sometimes outdated or wrong. As a result, the interpretation of such data has been problematic. The data limitations and suggestions that appeared in the 2001 Indiana Minority Health Report are repeated below. Unfortunately, much work remains to correct data deficiencies. (For further explanation of limitations below, please view the 2001 Minority Health Report at http://www.in.gov/isdh/publications/minority2001/.)

Limitations

- 1. Race and ethnicity categories are simplifications of complex issues.
- 2. Reporting entities do not consistently report race and ethnicity data.
- 3. Many agencies have not updated statistical information on minorities.
- 4. Race and ethnicity are considered causes of illness instead of risk factors.
- 5. There is a lack of consensus among reporting entities when defining and measuring race and ethnicity.
- 6. Death certificate classifications can reduce the actual number of minority deaths.

Suggestions

- By tracking race, ethnicity, and socioeconomic status, researchers can determine causative agents or the reasons why morbidity and mortality differ among particular racial and ethnic subgroups.
- Develop a protocol for federal, state, and local health agencies to ensure accurate
 and consistent reporting of race and ethnicity. Creating standard reporting
 measures and effective guidelines on how to collect, research, and report data will
 make a difference.
- Health agencies and representatives should become culturally competent to help in eliminating health disparities and providing necessary programs to at-risk health populations.

Suggestions that Were Remedied Since 2001

Due to federal bioterrorism funding, all of Indiana's 94 local health departments have access to 2001 or later technologies and Web capabilities, which allows them to access more statistical information on minorities. The ISDH Web site has data and statistics readily available, including mortality and natality, cancer incidence and mortality, results from the Behavioral Risk Factor Surveillance Survey, maternal and child health reports, State plan to control diabetes, minority health reports and plan, and information about

Indiana's health professions and medically underserved areas at http://www.in.gov/isdh/index.htm.

Current Data Limitations

Sheila Thorne, senior program officer at the Summit Health Institute for Research and Education, stated, "Rapidly changing demographics no longer make (addressing health disparities) an option." Thorne went on to say, "It's an imperative, not only for the survival of your institution, but for the improvement of quality outcomes in terms of public health."

Eliminating health disparities and ensuring equal quality of care continue to be the overarching goals for minority health. Data play such a key component in ensuring definite changes in current practices of health care, data collection, and reporting of reliable data. The following are just a few issues that come into play when examining current data limitations.

Consistency

To date, there is no set protocol for federal, state, and local health agencies in data collection. Data collected through the observation of untrained observers, or from self-reported survey instruments or administrative forms may always have limitations that render them somewhat unreliable.

Inadequacies in the quality, completeness, and availability of the information also restrict the use of the data by the ISDH. The lack of a uniform data collection method makes obtaining an accurate and specific description of race discrimination in the health care system extremely difficult.

Small Numbers

A primary concern is the issue of small numbers and the caution that needs to be taken in interpreting analyses conducted with counts so small that they will most likely yield results that are statistically insignificant.

Although efforts were made to use the best available data and methods to produce the 2004 Indiana Minority Health Report, the process does leave room for error in the estimates. The potential for error will be greatest for the smallest population groups, particularly the smaller race groups.

Is Collection of Race and Ethnicity Legal?

Despite the apparent benefits and need, many perceive that there are legal barriers to collecting such data and believe that Title VI of the Civil Rights Act of 1964, federal regulations, and/or state laws or regulations prohibit these entities from collecting racial and ethnic data.

Title VI of the Civil Rights Act of 1964 neither prohibits nor mandates the collection of racial and ethnic data. In Madison-Hughes v. Shalala (1996), the United States Court of Appeals for the Sixth Circuit held: (1) Title VI prohibits discrimination on the grounds of race, color, or national origin, but neither the language of Title VI nor applicable regulations require a health agency routinely collect racial and ethnic data; and (2) data collection is a means of ensuring compliance with Title VI, but the collection of racial and ethnic data and the methodology of data collection is not mandatory, but left to the collector's discretion.

The Health Insurance Portability and Accountability Act (HIPAA) privacy rule recognizes the importance of public health authorities being able to collect health care data to carry out their public mission. Therefore, the rule "permits covered entities to disclose protected health information without authorization for specified public health purposes."

If a state entity is legally authorized to receive reportable health information from health care providers, HIPAA allows providers to submit the required data elements to the state entity without patient authorization. HIPAA recognizes that legally authorized reporting of data is a legitimate public health activity and does not want to impede with this procedure.

Looking at More than Chronic Disease

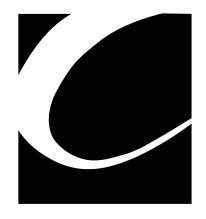
When examining minority health, most researchers or health agencies tend to focus on chronic disease (heart, stroke, cancer, etc.) but never really explore in great detail infectious diseases. Infectious diseases are considered a major cause of illness, death, and disability. Eliminating racial and ethnic disparities is a part of many objectives for *Healthy People 2010*.

The National Electronic Telecommunications System for Surveillance (NETSS) is the database used to report nationally notifiable infectious diseases. The NETSS system is maintained by the Centers for Disease Control and Prevention (CDC). Incidence rates for 8 out of 42 different infectious diseases were at least two times greater for Blacks than for whites. This is another piece that can help health officials and policymakers address disparities in these disease rates among racial and ethnic minorities, encouraging the need for even more change to close the gaps in data reporting. Of the 1,362,628 infectious disease cases reported in 2002 throughout the U.S., 70 percent of the cases provided racial data, and 65 percent of the cases provided ethnicity.

Those diseases with the higher incidence rates for Blacks were gonorrhea, shigellosis, syphilis, chlamydia, streptococcus pnuemoniae, typhoid, and hepatitis B. American Indians also have a higher incidence rate for infectious disease. In 2002, their incidence rate for salmonellosis and shigellosis was higher than any other race or ethnicity.

Observational Data Collection

Those who collect data also have a responsibility to reduce limitations of data. There are facilities and other health agencies that do not ask their clients or do not record race and ethnicity. This leads to data being misreported or not being reported at all. It is best if key personnel who will be collecting demographic information are trained on the proper way of collecting data so that it is not offensive to ask. Explaining the importance of data collection will help clients be more at ease in revealing race and ethnicity. Asking ethnicity first, then race, will help alleviate the dearth of ethnicity data on forms, surveys, and other data collection instruments. Assumption of race or ethnicity should not be made unless absolute necessary. Individuals should have the choice and right to reveal their racial and ethnic identity and also the right to refuse. The Indiana State Department of Health should continue to fulfill its charge under Indiana Code 16-19-10 and Indiana Code 16-46-11-1(7) to increase the amount of data available to assess minority health in Indiana.



Summary

There is increasing evidence that more lives could be spared by eliminating health disparities. From 1991 to 2000, more than 886,000 deaths could have been prevented if African Americans had received the same care as whites, according to an analysis in the December 2004 issue of the *American Journal of Public Health*. The study estimates that technological improvements in medicine—including better drugs, devices, and procedures—averted only 176,633 deaths for all races and ethnicities during the same period.

Steven H. Woolf, lead author and director of research at Virginia Commonwealth University's Department of Family Medicine, stated that means, "five times as many lives can be saved by correcting the disparities [in care between whites and Blacks] than in developing new treatments."

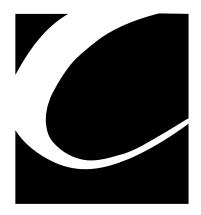
Reduced access to health care does not account for all the racial disparity in preventable deaths. Racial and ethnic minorities, in particular Blacks or African Americans, have greater frequency of some diseases; some of this greater morbidity results from education and income level, environment, and access to health care. The challenge, the authors said, is to deliver the same quality health care to everyone, despite these factors.

If health disparities continue to grow, there will be an increase in earlier deaths, greater decrease in quality of life, further loss of economic opportunities, and continuance of injustice. Data and data analysis will be of greatest use when government agencies and policymakers become aware and make actual effective changes to eliminate health disparities.

Once adequate data is acquired and proper analysis discloses information concerning the demographic characteristics of Hoosiers that are in need of better quality of health services, it will be necessary to design programs and base funding allocations on the objective needs demonstrated through the data.

Currently, racial and ethnic data is not routinely collected by many health service deliveries (local health departments, hospitals, clinics, etc.). The lack of data on the race and ethnicity of people being treated is a major barrier to performance measurement and clinical quality improvement efforts. The limited information available continues to show how much more racial and ethnic minorities suffer obstructed access to health services and poor quality of care.

Indiana must act to close the gap of health disparities. This can be accomplished by using guides such as the Healthy Indiana Minority Health Plan and other aids that will help make Indiana healthier, more equal, and a better place to live.



Bibliography, Data Resources, and Helpful Web Sites

Statistics

2002 Indiana Mortality Report

United States Census Bureau www.census.gov

National Center for Health Statistics (NCHS), Health U.S. www.cdc.gov/nchs

References

- 1. Committee on Quality of Health Care in America, Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C.: National Academy Press, 2001.
- 2. Smedley BD, Stith AY, Nelson AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, D.C.: National Academy Press, 2002.
- 3. Racial/Ethnic Differences in Cardiac Care: The Weight of the Evidence. Washington, D.C.: Henry J. Kaiser Family Foundation, 2002.
- 4. Ayanian JZ, Landrum MB, Guadagnoli E, Gaccione P. Specialty of Physicians Providing Ambulatory Care and Mortality Among Elderly Patients after Myocardial Infarction. N Engl J Med 2002;347:1678-1686.
- 5. Katon W, Robinson P, Von Korff M, et al. A Multifaceted Intervention to Improve Treatment of Depression in Primary Care. Arch Gen Psychiatry 1996;53:924-932.
- 6. Wells KB, Sherbourne C, Schoenbaum M, et al. Impact of Disseminating Quality Improvement Programs for Depression in Managed Primary Care: A Randomized Controlled Trial. JAMA 2000;283:212-220. [Erratum, JAMA 2000;283:3204.]
- Rubenstein LV, Jackson-Triche M, Unutzer J, et al. Evidence-based Care for Depression in Managed Primary Care Practices. Health Aff (Millwood) 1999;18:89-105.
- 8. Margolis KL, Lurie N, McGovern PG, Tyrrell MS, Slater JS. Increasing Breast and Cervical Cancer Screening in Low-income Women. J Gen Intern Med 1998;13:515-521.
- 9. LaVeist TA, Morgan A, Arthur M, Plantholt S, Rubenstein M. Physician Referral Patterns and Race Differences in Receipt of Coronary Angiography. Health Serv Res 2002;37:949-962.

- 10. HANYS Breast Cancer Demonstration Project. Rensselaer: Healthcare Association of New York State, 2002. (Accessed October 30, 2002, at http://www.hanys.org/quality_index/Breast_Cancer_Project/pnresourcekit.htm.)
- 11. Bodenheimer T, Wagner EH, Grumbach K. Improving Primary Care for Patients with Chronic Illness. JAMA 2002;288:1775-1779.
- 12. *Health Disparities Collaboratives Training Manual*. Washington, D.C.: Health Disparities Collaboratives, 2002. (Accessed October 30, 2002, at (http://www.healthdisparities.net/resources.html.)
- 13. Frankel RM, Stein T. Getting the Most out of the Clinical Encounter: The Four Habits Model. J Med Pract Manage 2001;16:184-191.
- 14. Fiscella K, Franks P, Gold MR, Clancy CM. Inequality in Quality: Addressing Socioeconomic, Racial, and Ethnic Disparities in Health Care. JAMA 2000;283:2579-2584.
- 15. Minority Health in America: Findings and Policy Implications from the Commonwealth Fund Minority Health Survey. Hogue, Carol J. R. 2000
- 16. *Healthy Indiana A Minority Health Plan for the State of Indiana: HEAL the Gap.* Minority Health Advisory Committee; Indiana State Department of Health, 2003. http://www.in.gov/isdh/publications/minority-health/mh_plan_april_2003.pdf
- 17. Bach PB, Pham HH, Schrag D, Tate RC, Hargraves JL. Primary Care Physicians Who Treat Blacks and Whites. N Engl J Med 2004;351:575-584.
- 18. Department of Health and Human Services. *Healthy People 2010: Understanding and Improving Health*. 2nd ed. Washington, D.C.: Government Printing Office, November 2000.
- 19. Laveist TA, Nuru-Jeter A. Is Doctor-Patient Race Concordance Associated with Greater Satisfaction with Care? J Health Soc Behav 2002;43:296-306.



African American/Black

- In 2001, the age-adjusted death rate for African Americans was 31 percent higher than for whites. The life expectancy for whites exceeded the life expectancy for African Americans by 5.5 years (77.7 for whites vs. 72.2 for African Americans).
- In 2001, the age-adjusted death rate for African Americans was higher than whites for cardiovascular disease, stroke, cancer, chronic lower respiratory disease, influenza and pneumonia, chronic liver disease, diabetes, HIV/AIDS, accidents, and homicide.
- 2.8 million African Americans have diabetes. On average, African Americans are twice as likely to have diabetes as whites of similar age.
- African Americans with diabetes experience kidney failure about four times more often than whites with diabetes.
- In 2001, more than 77,000 African Americans died from heart disease (leading cause of death), accounting for 27 percent of all African-American deaths.
- African Americans have a higher prevalence of hypertension than persons of any other racial or ethnic group.
- African-American women have a higher rate of overweight and obesity than persons of any other racial or ethnic group.
- African Americans have almost twice the risk of first-ever stroke as whites. In 2001, the death rate from stroke for African Americans was 78.8 per 100,000 vs. 56.0 for whites.
- Overall, African Americans are more likely to develop cancer than persons of any other racial or ethnic group, and have a higher cancer death rate than persons of any other racial or ethnic group.
- The prostate cancer incidence rate among African-American men is 66 percent higher than the rate among white men, and the prostate cancer death rate is two or more times higher among African Americans than men of any other racial or ethnic group.
- African-American women have a higher mortality rate from breast cancer than women of any other racial or ethnic group.
- In 2002, more than half of all AIDS cases diagnosed were among African Americans.
- In 2001, the HIV/AIDS death rate for African Americans was more than 10 times higher than for whites (22.8 per 100,000 vs. 2.1 per 100,000 for whites).
- In 2001, the infant mortality rate for African Americans was more than twice as high as for whites (13.3 per 1,000 live births vs. 5.7 per 1,000 live births for whites).
- In 2004, 22,635 African Americans were on the waiting lists for organ transplants (nearly 27 percent of the total).
- In 2004, 36 percent of those on the kidney transplant waiting list were African American.

• African Americans ages 65 and older have lower rates of influenza and pneumonia immunizations than whites. About 70 percent of elderly whites received the flu vaccine in 2003, compared to 49 percent of elderly African Americans. About 60 percent of elderly whites received a pneumonia vaccine in 2003, compared to 37 percent of elderly African Americans.

^{*} Note: All data provided for quick facts is an excerpt from the Office of Minority Health closing The Health Gap (http://www.healthgap.omhrc.gov)

American Indian/Alaska Native

- On average, American Indians/Alaska Natives are 2.3 times as likely to have diabetes as whites of similar age.
- Cancer is the second leading cause of death for American Indians/Alaska Natives, accounting for 18
 percent of all American Indian deaths.
- In 2001, more than 2,400 American Indians/Alaska Natives died from heart disease (leading cause of death), accounting for 20.1 percent of all American Indian and Alaska Native deaths.
- Among American Indians/Alaska Natives ages 18 and older, 63.7 percent of men and 61.4 percent of
 women have one or more cardiovascular disease risk factors (hypertension, current cigarette smoking,
 high blood cholesterol, obesity, or diabetes).
- American Indians/Alaska Natives ages 35-44 have almost twice the relative risk of stroke death when compared with the U.S. white population.
- Among American Indians/Alaska Natives ages 45-74, 26.8 percent of men and 27.5 percent of women have high blood pressure.
- Among American Indians/Alaska Natives ages 45-74, 25.9 percent of men and 31.3 percent of women are overweight.
- Among American Indians/Alaska Natives ages 45-74, 35.5 percent of men and 41.2 percent of women are obese.
- In 2001, the HIV/AIDS death rate for American Indians/Alaska Natives was 1.3 times higher than for whites.
- The infant mortality rate for American Indians/Alaska Natives is 70 percent higher than for whites.
- Statistics for 2002 show that, for most age groups, American Indians have higher rates of illicit drug, marijuana, smokeless tobacco, and tobacco use than whites.
- The use of illicit drugs within the past 30 days in American Indian teenagers (12-17) is almost double that for whites (20.9 percent vs. 12.6 percent).
- In 2002, more than half of all new AIDS cases among American Indian women were due to injection
 drug use or sex with an injection drug user. In the male population, 19 percent of all new AIDS cases
 was due to injection drug use.

^{*} Note: All data provided for quick facts is an excerpt from the Office of Minority Health closing The Health Gap (http://www.healthgap.omhrc.gov)

Asian American/Pacific Islander

- Diabetes is the fifth leading cause of death in the Asian-American and Pacific Islander population.
 Prevalence data for diabetes among this group are limited, but some subpopulations are at increased risk for diabetes. Native Hawaiians, Japanese, and Filipino adults living in Hawaii were about two times more likely to have been diagnosed with diabetes as white residents.
- Asian-American and Pacific Islander women are more than three times as likely to fall ill from stomach cancer as white women (13.1 vs. 4.0).
- In 2001, 9,428 Asian Americans/Pacific Islanders died from heart disease, accounting for 25.4 percent of all Asian-American/Pacific Islander deaths.
- Asian Americans/Pacific Islanders at ages 35-44 have a 1.3 times higher relative risk of stroke death as compared to the U.S. white population.
- 73 percent of Japanese-American men ages 71-93 have high blood pressure.
- Among Asian Americans/Pacific Islanders ages 18 and older, 36.7 percent of men and 27.1 percent of women are overweight or obese.
- The infant mortality rate for Native Hawaiians is 28 percent higher than for whites.

^{*} Note: All data provided for quick facts is an excerpt from the Office of Minority Health closing The Health Gap (http://www.healthgap.omhrc.gov)

Hispanic/Latino

- As of 2002, two million Hispanic adults ages 20 and older—about 8.2 percent of the population—have diabetes. On average, Hispanics/Latinos are 1.5 times more likely to have diabetes than whites of similar age.
- Diabetes is more prevalent in older Hispanics, with about 25 to 30 percent of Hispanics ages 50 or over having the disease.
- In 2001, more than 27,000 Hispanics died from heart disease (leading cause of death), accounting for nearly 24 percent of all Hispanic deaths.
- Mexican-American women have higher cardiovascular disease risk factors than white women of comparable socioeconomic status.
- Hispanics/Latinos between the ages of 35-64 have about 1.3 times higher risk of stroke death when compared with the U.S. white population.
- More Mexican-American men are overweight than men in any other racial or ethnic group.
- The rate of cervical cancer is 2.5 times higher for Hispanic/Latino women than for white women.
- In 2001, the HIV/AIDS death rate for Hispanics/Latinos was nearly three times higher than for whites (6.2 per 100,000 vs. 2.1 per 100,000 for whites).
- Although the infant mortality rate for Hispanic/Latino infants is less than the rate for white infants, within the Puerto Rican subgroup, the rate of infant deaths from Sudden Infant Death Syndrome is 1.5 times higher than for whites.
- Nearly 13,000 Hispanics/Latinos are on waiting lists for organ transplants, accounting for 15 percent of all patients on organ transplant waiting lists.
- Hispanics/Latinos ages 65 and older have lower rates of influenza and pneumonia immunizations than
 whites. About 70 percent of elderly whites received the flu vaccine in 2003, compared to 47 percent of
 elderly Hispanics/Latinos. About 60 percent of elderly whites received a pneumonia vaccine in 2003,
 compared to 31 percent of elderly Hispanics/Latinos.

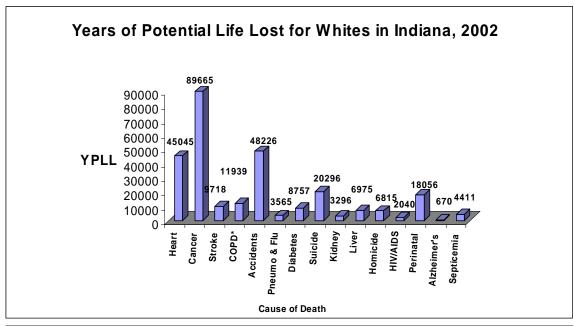
^{*} Note: All data provided for quick facts is an excerpt from the Office of Minority Health closing The Health Gap (http://www.healthgap.omhrc.gov)

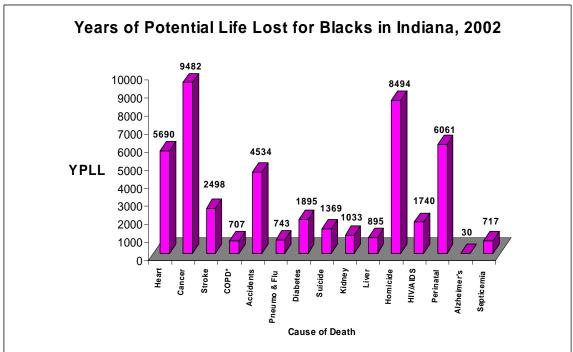


APPENDIX B

Years of Potential Life Lost, Indiana, 2002

The following tables report Years of Potential Life Lost (YPLL) for specific diseases and by race and ethnicity. These tables show the specific diseases and illustrate years lost due to the particular cause of death.





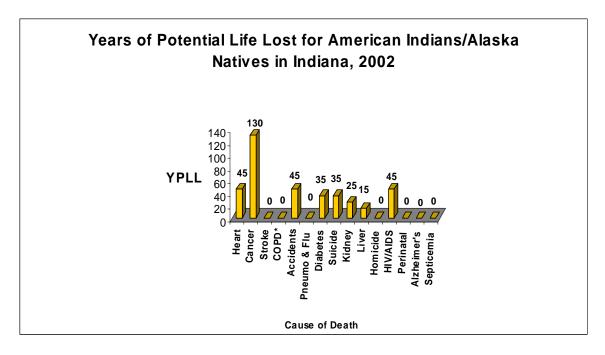
Note: In 1995-2002, the data were collected by combining Asian and Native Hawaiian or Pacific Islander categories to make the (A/PI) category as will be seen in the leading causes of death graphs.

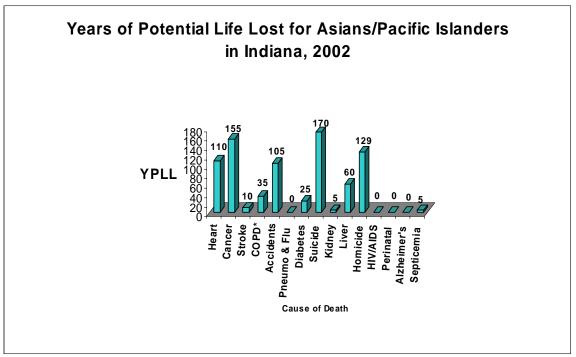
Numbers vary due to population of race or ethnic group being compared.

Rates are per 100,000 population.

Total death numbers that are below 20 are not statistically sound.

*Chronic Obstructive Pulmonary Disease



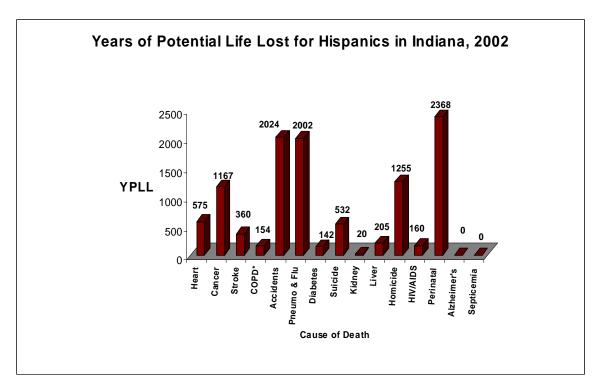


Note: In 1995-2002, the data were collected by combining Asian and Native Hawaiian or Pacific Islander categories to make the (A/PI) category as will be seen in the leading causes of death graphs.

Numbers vary due to population of race or ethnic group being compared. Rates are per 100,000 population.

Total death numbers that are below 20 are not statistically sound.

*Chronic Obstructive Pulmonary Disease



Note: In 1995-2002, the data were collected by combining Asian and Native Hawaiian or Pacific Islander categories to make the (A/PI) category as will be seen in the leading causes of death graphs.

Numbers vary due to population of race or ethnic group being compared.

Rates are per 100,000 population.

Total death numbers that are below 20 are not statistically sound.

Hispanic is an ethnicity and includes all races.

*Chronic Obstructive Pulmonary Disease